



King's Research Portal

DOI:

[10.1111/bjhp.12235](https://doi.org/10.1111/bjhp.12235)

Document Version

Peer reviewed version

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Picariello, F., Ali, S., Foubister, C., & Chalder, T. (2017). 'It feels sometimes like my house has burnt down, but I can see the sky': A qualitative study exploring patients' views of cognitive behavioural therapy for chronic fatigue syndrome. *British Journal of Health Psychology*, 22(3), 383-413. <https://doi.org/10.1111/bjhp.12235>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

“It feels sometimes like my house has burnt down, but I can see the sky”: A qualitative study exploring patients’ views of CBT for Chronic Fatigue Syndrome.

Authors:

Federica Picariello, MSc

Institute of Psychiatry, Psychology, and Neuroscience, King’s College London; South London and Maudsley NHS Foundation Trust

Sheila Ali, MSc

South London and Maudsley NHS Foundation Trust

Caroline Foubister, MSc

Institute of Psychiatry, Psychology, and Neuroscience, King’s College London; South London and Maudsley NHS Foundation Trust

Professor Trudie Chalder, PhD, DipBehavPsych *

***Corresponding author:**

Department of Psychological Medicine, Institute of Psychiatry, King’s College London

Email: Trudie.chalder@kcl.ac.uk

Postal address: Department of Psychological Medicine, Institute of Psychiatry, King’s College London, Weston Education Centre, 10 Cutcombe Road, London SE5 9RJ

Abstract

Objectives: Cognitive Behavioural Therapy (CBT) is currently the first line treatment for Chronic Fatigue Syndrome (CFS). Even though the results from trials are promising, there is variability in patient outcomes. The aim of this study was to explore the experiences of patients with CFS who undertook CBT at a specialist service for CFS. **Design:** This was a qualitative study. **Methods:** Thirteen CFS patients, approaching the end of CBT, participated in semi-structured interviews. In addition, participants were asked to rate their satisfaction with CBT and perceived level of improvement. The data were analysed using inductive thematic analysis. **Results:** The majority of participants were satisfied with treatment and reported marked improvements. This was evident from the ratings and corroborated by the qualitative data, yet recovery was in general incomplete. Participants often disclosed mixed feelings towards CBT prior to its start. Behavioural aspects of treatment were found useful, while participants were more ambivalent towards the cognitive aspects of treatment. The tailored nature of CBT, and therapist contact were important components of treatment, which provided participants with support and validation. Engagement and motivation were crucial in order to benefit from CBT, as well as the acceptance of a bio-psychosocial model of CFS. Illness beliefs around CFS were also discussed throughout the interviews, possibly impeding engagement with therapy. **Conclusions:** The results suggest that various factors may moderate the effectiveness of CBT, and a greater understanding of these factors may help to maximize benefits gained from CBT.

Introduction

Chronic Fatigue Syndrome (CFS) is characterised by persistent and debilitating fatigue, and symptoms such as sleep disturbance, pain and impaired concentration (Fukuda et al.,

1994). It affects around 0.5% of the UK population (Joyce, Hotopf, & Wessely, 1997) and at least 0.2-0.4% of the population worldwide (Baker & Shaw, 2007a).

The cognitive behavioural model of CFS posits that unhelpful cognitions such as catastrophizing and symptom focusing drive disability and increase the severity of CFS symptoms (Chalder, Butler, & Wessely, 1996; Surawy, Hackmann, Hawton, & Sharpe, 1995). In support of this, studies have shown that unhelpful cognitions and avoidance of physical activity can exacerbate and maintain CFS symptoms (Cella, White, Sharpe, & Chalder, 2013; Petrie, Moss-Morris, & Weinman, 1995). Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) are recommended treatments for CFS (Baker & Shaw, 2007b). CBT involves working with the patient to challenge unhelpful cognitions and change maladaptive behavioural patterns, which may include reducing avoidance behaviours and improving sleep (Burgess, Andiappan, & Chalder, 2012).

There is a large amount of evidence from meta-analyses and a recent large randomised-controlled trial showing that CBT is effective in reducing CFS symptoms and improving functioning (Castell, Kazantzis, & Moss-Morris, 2011; Price, Mitchell, Tidy, & Hunot, 2008; White et al., 2011). A Cochrane review and meta-analysis of 15 studies of CBT for CFS found that CBT was more effective than psychological therapies such as relaxation or education, or usual care. This review also showed that around 40 per cent of CFS patients report marked improvements in fatigue and social adjustment after receiving CBT (Price et al., 2008). The more recent Castell et al. (2011) review found that CBT and graded exercise therapy were equally effective, with CBT showing better outcomes for depression. Although the effects of treatments outside the confines of a randomised-controlled trial are slightly reduced, CBT has also been found to be effective in routine clinical practice (Quarmby, Rimes, Deale, Wessely, & Chalder, 2007; Stahl, Rimes, & Chalder, 2014).

Despite the positive results of CBT for CFS, there are still some patients who do not benefit from CBT. A number of predictors of outcome following CBT have been explored in the literature. For example, longer illness duration, older age, receipt of benefits, and lower

cortisol levels are factors that may act as markers of symptom persistence (Bentall, Powell, Nye, & Edwards, 2002; Flo & Chalder, 2014; Joyce et al., 1997; Quarmby et al., 2007; Roberts et al., 2010; Wearden, Dunn, Dowrick, & Morriss, 2012), possibly restricting the extent of CBT-related improvements. Additionally, an examination of subtypes of CFS revealed that a poor response to CBT was evident in patients who reported anxiety, pain, and greater symptom focusing (Cella, Chalder, & White, 2011).

Other modifiable factors that may explain CBT outcomes are working alliance, and the therapist effect (e.g. Heins, Knoop, & Bleijenberg, 2013; Horvath, Del Re, Flückiger, & Symonds, 2011). In CBT, working alliance refers to the collaboration between the therapist and the client to identify negative thoughts through Socratic reasoning and homework assignments (Dattilio & Hanna, 2012). Working alliance, more specifically agreement on therapy content, together with outcome expectations, seemed to facilitate changes in fatigue-perpetuating factors, possibly through increased engagement with treatment, consequently leading to reductions in post-treatment fatigue (Heins et al., 2013). The evidence on therapist effect in CBT is mixed (Cella, Stahl, Reme, & Chalder, 2011; Crits-Christoph et al., 1991; Heins et al., 2013; Wiborg, Knoop, Wensing, & Bleijenberg, 2012).

There is also some evidence that illness beliefs may affect the extent to which patients accept the CBT model of CFS (Heins et al., 2013). For example, physical illness attributions may effect engagement with therapy (Sharpe, Hawton, Seagroatt, & Pasvol, 1992). A qualitative study of the illness beliefs of CFS patients found that, alongside viral triggers, patients acknowledged that stress may contribute to the development and maintenance of CFS (Clements, Sharpe, Simkin, Borrill, & Hawton, 1997). Nonetheless, psychological factors were rarely perceived as dominant in this process, and some patients expressed open disapproval towards psychological explanations of CFS (Clements et al., 1997), possibly playing a role in early withdrawal from CBT or disengagement throughout the sessions (Prins et al., 2001; Timmer, Bleichhardt, & Rief, 2006).

Most research in this area has been quantitative. However, a qualitative approach may yield richer data on the experience of patients who have received CBT (Dennison, Stanbrook, Moss-Morris, Yardley, & Chalder, 2010). Dennison et al. (2010) have used a qualitative approach to investigate the experience of CBT and Psycho-Education in children and families of adolescents with CFS. However, the current study is the first to employ a qualitative methodology to explore in more depth the CBT experience of adult CFS patients. The objectives of this study were to explore reasons for why some patients engage in treatment more than others, and to assess whether CBT meets patients' needs. This is key in ensuring that more patients benefit from CBT and that resources are used optimally.

Method

Design

This was a qualitative study. Participants were recruited from a specialist outpatient unit for CFS.

Treatment

All participants received face-to-face CBT from experienced therapists, guided by a standardized CBT manual, and with regular clinical supervision. The therapeutic model has been previously described elsewhere (e.g. Burgess et al., 2012). Sessions were typically fortnightly, with up to 15 sessions, depending on progress and agreement between the client and therapist. Participants were offered follow-up face-to-face sessions at 3 months, 6 months and 12 months after the end of treatment.

Procedure

Informed consent was obtained from all study participants. Participants were recruited consecutively, and invited to participate if they had finished CBT or were in the follow-up stage. Out of thirty-two patients approached for participation, 14 (44%) consented of which 13 were interviewed (41%). Participants were excluded from the study if they did not have a diagnosis of CFS.

Interviews were conducted either face-to-face or by telephone. Interviews were semi-structured, and participants' responses shaped the direction and further questions of the interviewer (*Figure 1*). Interviews were digitally recorded and transcribed verbatim.

Demographic data were also collected from participants, and they were asked to rate their satisfaction with treatment and the extent to which they felt they had improved. Satisfaction was rated on a seven-point Likert scale (from 0=Very Dissatisfied to 6= Very Satisfied), while improvement on a six-point scale from 0= Very Much Worse to 5=Very Much Better (Guy, 1976).

It has previously been recommended that qualitative studies require a minimum sample size of at least 12 to reach data saturation (Braun & Clarke; Fugard & Potts, 2014; Guest, Bunce, & Johnson, 2006) Therefore a sample of 13 was deemed sufficient for the qualitative analysis and scale of this study.

Analysis

Transcripts were analysed using inductive thematic analysis (Braun & Clarke, 2006). This included extracting initial codes from the text, incorporating these emergent codes into broader themes, and development of a coding manual (Appendix A). Some techniques from the Grounded Theory qualitative analysis framework were also used 1) constant comparison 2) generating a storyline and 3) diagramming (*Figure 2*). The data were coded separately by two of the authors. Any discrepancies were discussed, and the themes were modified accordingly.

Results

Table 1 shows the demographic characteristics of the sample, and Table 2 shows participant ratings of satisfaction and global improvement post-CBT.

Findings from the Thematic Analysis

Six main themes emerged through the thematic analysis (Table 3) and are discussed in more detail below. *Figure 2* is a thematic diagram of the identified themes and subthemes.

1. Hopes and Expectations

One theme that emerged was related to participants' expectations about CBT and how expectations were shaped by previous experiences.

1.1. Mixed feelings

Before beginning CBT, many participants reported feeling uncertain about what it would entail and wondering if it would be beneficial. However, many participants had no preconceived ideas and reported mixed feelings about starting CBT. They hoped that CBT would help, but also expressed some scepticism:

"I thought 'yes it's got to do something', they wouldn't have these clinics if CBT didn't work...a lot of it you still don't know what to expect from it 'cause you just think 'it's a whole lot of talking...how's that really going to help?'" (pt10).

Some participants expected that CBT would be a solution to their problems: *"I was hoping to be cured"* (pt7). However, in some cases the expectation of a cure was linked to poorer outcomes and less satisfaction with CBT, suggesting that some participants were disappointed with the recurrence of CFS symptoms after CBT.

Frequently, participants reported feeling *"confused and apprehensive"* (pt2) and *"nervous, and...not knowing what to expect"* (pt14) at the beginning of therapy. However, as the process of treatment carried on, their experience transformed. Feelings of apprehension were quickly replaced by feeling *"at ease"* (pt14), and being *"used to... what the process was"* (pt2).

The majority of participants reported high levels of satisfaction with treatment, and in some cases felt that the treatment exceeded their expectations:

“I’ve changed my mind about it now but I wasn’t sure about CBT to begin with...It has been really useful...I’m really pleased with it ...I’m really surprised but I did think it was useful” (pt4).

1.2. Previous experiences of treatment

Previous experiences of treatment may also have shaped expectations of CBT. The experiences of participants were extremely varied, with some having tried psychological therapies, and others having tried alternative treatments. Participants with previous unsuccessful experiences of treatment had greater hopes for CBT:

“I went to all sorts of people and I tried everything you can think of but nothing ever worked” (pt14).

In fact, some participants perceived CBT to be their last resort:

“I needed something, I did not know whether CBT was going to be it. But I just knew that nothing else I was doing was improving things...I just really hoped that it would improve things for me” (pt10).

2. Real, Not Imagined

This was a major theme that emerged and it encompasses comments about the experience of living with CFS and the important issue of feeling validated.

2.1. Validation and the process of diagnosis

Many participants reported difficulty with the process of obtaining a diagnosis. Some were misdiagnosed with other illnesses, which seemed to contribute to a feeling of frustration and disillusionment with the healthcare system:

“there were a lot of blood tests until the point that I was like ‘I am not doing another blood test, you’ve kind of got everything you need’” (pt9).

In fact, one participant felt that the battle to get diagnosed, and the lack of recognition and poor communication from healthcare professionals, could alienate patients from CBT:

“then they might have a bit more positive response from the patients, but not when ...it is put to most patients that ‘it is all in your head...and see a psychiatrist to sort it out’” (pt10).

One participant felt that getting diagnosed and referred to the clinic was *“almost part of the cure in itself”* (pt9), which emphasises how validation can be of therapeutic value for this patient population. It seems that getting diagnosed might be the first step towards improvement, yet, the lengthy process of obtaining a diagnosis can potentially act as a barrier to CBT uptake.

Treatment was also a source of validation. Participants stated that CBT helped them to feel understood and to reaffirm that their suffering is real and recognized:

“it makes you feel like you didn’t spend years of your life making this up and it makes you feel normal and ...human” (pt13).

Moreover, participants also repeatedly shared their feeling that CBT provided a non-judgemental environment to express themselves:

“she [therapist] never criticized, and I suppose I felt she would...[she] would hear you out and wasn’t there to criticise you” (pt14).

This allowed participants to disclose to therapists how debilitating CFS can be:

“the therapist was crucial because this was a human being who’s got it...I wasn’t having to justify myself...so if I said I couldn’t get out of bed it was fine and it made sense and that was what I needed” (pt9).

2.2. Causal attributions

The majority of participants, especially those who reported a lack of improvement following CBT, attributed their CFS to an exclusively organic cause. For example, some participants suggested that the treatment should consist of more physical or medical aspects such as: *“Vitamin D deficiency [testing]” (pt7)*, or *“look[ing] at nutrition” (pt2)*, or further blood testing. This type of exclusively physical attribution may act as a barrier to engagement with CBT. For example, one participant displayed open disapproval towards the psychological explanation provided in CBT:

“there’s just something around some of the material that...might benefit from ...thinking more explicitly about ‘actually is this going to alienate someone who does believe in a physical [cause]’...there’s a fine line between that and saying actually the things that you are doing are just making you ill, like saying ‘oh well if you stay in bed for a long time you will feel dizzy or if you stay in bed for a long time you know your muscles will waste away’...because actually in my case for example things happened when I didn’t have any prolonged bed rest” (pt5).

However, many participants acknowledged both physical and psychological explanations for their fatigue:

“I don’t know if it was just over doing things, when I went through the CBT with [the therapist], I [be]came aware of how much I had on my plate. But at the same time, I also had some Hep B jabs because my immunity was low, so they gave me the full set of boosters” (pt10)

2.3. Stigma

Another major subtheme which emerged was related to the stigma associated with mental health and psychological treatments. Many participants perceived that their illness did not belong to the realm of mental health problems:

“I don’t really want to be seen to be in that group of people...I am not having mental health problems” (pt10).

Another participant reported *“feel[ing] stigmatised... the [psychiatric hospital] was somewhere where people went when they were seriously ill... I felt very ashamed” (pt12).*

Many participants also reported difficulties communicating their experiences to healthcare professionals and relatives or friends:

“when...I had my first seizure and that’s when people started taking me seriously, before that no one believed me, and my mom just thought ‘you are just getting bullied that’s why you don’t want to go to school’. Doctors thought that I was just making it up” (pt13).

3. Collaborative Therapeutic Alliance

This was a dominant theme across all narratives, revolving around the role of the therapist in CBT, and what benefits face-to-face consultations can yield.

3.1. CBT as support

For many participants, CBT provided a source of support and a space for them to speak openly without being judged. Participants were comforted by the knowledge that the therapist was available to them if they needed help:

“It has been very comforting to know that I can pick up the phone or I could email [the therapist] to just say ‘hey I’m a bit concerned about this, what do you think?’” (pt12).

In fact, the simple act of talking to someone appeared to benefit participants, which emphasizes the importance of the therapist’s role within CBT.

“a lot of my life I’ve just had to get on with things and not talk about it... it would be boring to talk about it all the time but it’s probably nice to have a space where it’s alright to ...talk about the effect that it does have on my life” (pt5).

3.2 Rapport

Many participants valued building a relationship with the therapist and reported a preference for face-to-face consultations. Some participants found face-to-face sessions to be more personal, and felt that they were able to be more forthcoming:

“on the phone...you’ve got that barrier again, they can’t see you, and I just feel maybe I would’ve hidden...I wouldn’t have been as honest, I don’t think, if stuff was done over the phone” (pt10).

3.3 Personalised care

Participants also felt that the treatment was shaped by both the client and therapist, feeling in control and being able to contribute to and guide the content and structure of the sessions. On the whole, participants reported being satisfied with the content and structure of the sessions, and appreciated the fact that the therapy was adaptable to their needs. The patient-guided nature of CBT can be seen particularly well in the following quote:

“if I want to set the agenda for instance, I feel I can do that, if I had something that I particularly want to talk about... it feels very free in that regard” (pt12),

The majority of participants reported that the treatment was relevant to them and that the content of CBT was dictated by their needs:

“if there was another issue that I was like not able to problem solve myself, we went through problem solving stuff quite a lot ...Sometimes it was like ‘let’s look at how to deal with these sorts of situations generally’, and other times I came with specific stuff” (pt2).

This suggests that a personalised treatment approach may be more preferable to participants than a standardised treatment approach.

4. Motivation and Engagement

Another major theme that emerged was related to the importance of motivation and engagement with therapy as well as factors that may influence the effort invested into treatment by participants.

4.1 Acceptability of psychological explanations

An important facilitator of engagement with therapy was prior beliefs and attitudes towards CBT. Patients reported that the ability to be open and receptive towards CBT helped them to engage in therapy:

“possibly, I guess I am quite an open person and I’m quite self-aware anyway...and I guess for somebody who wasn’t, that didn’t really think about things on that level...it could’ve been harder for them to deal with the things that were being asked from them” (pt9).

Many participants reported that their acceptance of psychological explanations was crucial in the process of engagement (see also **subtheme 2.2**), as clearly evident in this comment:

“I think some people see it as sort ‘oh it means that it’s all sort of in your head, and it’s a purely psychological issue’, when it may or may not be the case, but it can still help people with chronic health conditions. So I think if you don’t buy into that, then it probably is going to be very helpful” (pt11).

4.2 Intrinsic motivation

Participants also recognised that in order to benefit from CBT, one must be ready to invest effort in it, and motivation must come from within:

“If I’m really committed to getting better myself, then I should” (pt5).

Another participant commented:

“You can’t just expect a magic pill or someone else to do everything for you, you’ve got to...at least give 50% into getting better” (pt10).

However, the ability of participants to invest effort might depend on illness severity and their personal circumstances at the time of therapy. Some participants felt that starting CBT was more suitable for them at a time when symptoms were less severe. For one participant, starting antidepressants before therapy was useful:

“they [antidepressants] actually did [give] me a good start because it lifted my down moods and helped me to focus better” (pt14).

4.3 Challenges of CBT

Even though most participants felt positive about the structure and content of CBT, some reported conflicting feelings about the CBT tasks. For example, participants found self-monitoring tasks useful, but at the same time found some tasks *“incredibly tedious”* (pt12), or found difficulties with the logistics of integrating CBT into their everyday schedule: *“sometimes it was hard to fit [activity monitoring sheets and sleep diaries] into your routine, because they would maybe require quite a lot of time that, if you are working full-time, and you are very tired, doesn’t always leave a lot of time for that kind of thing”* (pt11).

Nevertheless, participants generally did not report any significant practical barriers to session attendance, and were able to fit them around daily routines and responsibilities:

“Here I’m very lucky because it’s one bus so really it’s not difficult for me at all” (pt1),

And:

“I think my work has been quite understanding and flexible” (pt5).

5. Gain and Loss

This theme revolves around the skills participants gained through CBT and the loss they felt at having to give up activities as part of the process of change.

5.1 Gaining insight

Improvement was closely linked to a mastery of the self-monitoring process and an awareness of behaviours or cognitions that may be contributing to the fatigue:

“the mindfulness around one’s expenditure of energy was a very big thing for me... because I never gave any thought to how much [I do]...on a daily basis and actually really thought I didn’t do much” (pt12).

5.2 Gaining self-management strategies

Alongside gaining awareness, what seemed pivotal was learning to plan and manage activity according to one’s energy levels and wellbeing. This allowed participants to sustain improvements following CBT:

“I think over time that consistently what’s been missing that’s helped... I’ve been armed with tools to be able to handle it myself...preparing before the week hits, so I know where the points in the week are where it might be stressful and how to prepare for that” (pt9).

Therefore, participants felt that the change was achieved through a better understanding of patterns of activities that may be triggering fatigue, but also through having the skills to manage and plan ahead, and not to succumb when symptoms arise. These skills helped to counterbalance any apprehension of relapse.

5.3 Gaining self-compassion

Participants also mentioned that through CBT they found it easier to be compassionate to themselves. They allowed themselves to take breaks, thereby avoiding a ‘boom and bust’ pattern of behaviour:

“Planning your days so that YOU can manage it, rather than depending on someone else to plan your day, and to help you through because you need to be able to help yourself...and now I feel I know my limits better, and I know where I need to stop and rest” (pt14).

5.4 Losing favoured activities

For some participants, an unwanted consequence of developing a more consistent behavioural routine meant discontinuation of much-loved hobbies and activities. However, participants gained a sense of perspective and were able to see the costs and benefits of this approach:

“I found that very hard, and to not be active was very hard, because I’ve always been a very active sort of person... it kind of feels sometimes like my house has burnt down, but I can see the sky...I feel like I’ve lost a lot, but I’m still here” (pt12).

6. Change

This theme revolves around the nature of change following CBT, including the awareness of improvement following CBT, factors which helped to facilitate change, and the process of transitioning out of treatment after having seen these changes.

6.1 Usefulness of CBT-specific components

Participants consistently reported finding behavioural tasks, such as activity or sleep monitoring, to be helpful, facilitating the development of self-awareness:

“They [activity monitoring] were useful...because you think that you just do nothing all day or you do too much and actually writing it down and looking back at why I was tired was because I did that for 4 hours was quite useful” (pt4).

Feedback on the cognitive aspects of therapy was more mixed, with some perceiving it as crucial:

“The biggest part of the therapy was the cognitive, the challenging beliefs” (pt6).

Others felt that cognitive aspects of treatment were less useful, especially for the physical symptoms of CFS:

“tackling negative thinking...I don’t know how much it’s helped with pain or fatigue, just little changes but not really big” (pt3).

6.2 Awareness of change

Change was described as a gradual process, and often participants reported not being aware of the improvement: *“it was only when I got to the end that I realised that I’ve come quite a long way” (pt11)*. In fact, some participants reported that the improvement was more apparent to those around them, than to themselves:

“Other people have said it to me...definitely emotionally I’m completely different to what I was a year ago, and I suppose you yourself don’t always see it, do you?” (pt1).

One participant seemed to display some frustration towards the pace of change, and felt that at times she *“would put in the effort...but not see the results” (pt10)*.

Another participant described an overall improvement, which could not be attributed to a specific component of the therapy:

“you are making changes anyway, and you are making changes based on the recommendations of your therapist, the net effect is an improvement... but to say, ‘it’s because of this’, it’s not always easy to say...so it was difficult to be able to say ‘oh yeah, it is definitely that thing that made the difference’... it’s holistic” (pt12),

This holistic view of change was expressed succinctly by another participant:

“In the end everything had its purpose” (pt6).

6.3 Before and now

Descriptions of improvement following CBT all shared prominent characteristics. Participants who felt that they benefited from CBT often reported changes in wellbeing, for example:

“I went from not really walking very much to walking for 11 miles last weekend”
(pt11).

Despite the majority of participants reporting marked improvements in wellbeing, a minority felt that their improvement was only slight:

“Not hugely different I would say, but there’s just some things that have improved, I guess”
(pt3),

Another participant felt that they had not improved at all:

“I feel worse, but not because of CBT...I just think I feel worse because my health just generally degraded” (pt13).

Across all the interviews, the participants who reported improvements following treatment still felt that their wellbeing did not return to pre-morbid levels of functioning:

“I don’t know if I can honestly say ‘yeah I’m better now’...as in cured, as in this is gone”
(pt12).

6.4 Transitioning out of treatment

In general, participants were satisfied with the number of sessions that they received. The number of sessions was also tailored to one’s progress and needs (see **subtheme 3.3**).

pt9: “a year is good actually because it’s enough to see progress over a period of time”.

To some, the support of CBT acted as a sort of safeguard even when sessions were spread out over time:

“you’d go down to one [session] every three months, then one every six months, so if something was really not going very well, then you felt like... you weren’t completely on your own” (pt11).

However, many participants felt that they would have liked the support of additional sessions, if resources had permitted. Many participants feared a relapse and did not know how they would cope without being in CBT.

“I’m just so afraid of getting up one morning, tomorrow, next week, in a year’s time, and find that I can’t get out of bed, and I’m just so afraid of it coming back” (pt14).

Nonetheless, participants often felt that CBT provided the skills necessary to overcome such setbacks (see **Theme 5**):

“the Sunday I had what I felt was a real CFS symptom day, it felt exactly like I felt right back in the beginning...So I thought ‘no stop it, I am not going to go nuts,’ and I thought ‘alright I’ll laze in bed, I’ll read’, I think I got up for a couple of hours, but I felt tired so I went back to bed, got a few hours of sleep, woke up, felt a lot better” (pt10).

Many participants noted that because of the skills that they gained in therapy, the end of treatment marked a new beginning and they felt more in control of their life:

“I’m better at focusing on my days and my weeks ...I feel like I’ve got my life back at this point” (pt14).

Discussion

This was a qualitative study of adult CFS patients’ experiences of CBT. The majority of participants were satisfied with treatment and reported improvements in wellbeing. Many participants reported that therapy was a patient-guided, collaborative process, generic aspects of the CBT approach. They suggested that CBT allowed them to express themselves and work through difficulties in a non-judgemental, supportive setting. Moreover, many participants argued that it was necessary for them to be intrinsically motivated and put in

effort in order to reap the full benefits of CBT. Some participants suggested that full participation in CBT required open-mindedness and acceptance of a model of CFS which incorporated biological and psychosocial explanations of fatigue.

Participants appeared to value the behavioural tasks and goal setting that were used in CBT, helping them to monitor their own progress and to practice self-compassion. However, despite the majority of participants reporting significant improvements, there was a trend for participants to fear future relapse.

The findings of this study are in line with previous research, but also provide some new insights. For example, the majority of participants reported improvements in wellbeing after CBT and satisfaction with the outcome. This is supported by previous research on the effectiveness of CBT for CFS (Castell et al., 2011; Chambers, Bagnall, Hempel, & Forbes, 2006; Malouff, Thorsteinsson, Rooke, Bhullar, & Schutte, 2008; Price et al., 2008; Prins et al., 2001; Rimes & Chalder, 2005; Wessely, Hotopf, & Sharpe, 1998; Whiting et al., 2001).

Also, participants in this study valued the tailored approach of therapy, fundamental to CBT. This is in line with previous research which showed significantly higher effect sizes for individual CBT than for group-based CBT, because individual sessions can be more personalised (Bazelmans, Prins, Lulofs, Van der Meer, & Bleijenberg, 2005; Houdenhove & Luyten, 2008). Across the literature, the importance of tailored treatment approaches has been long advocated (Prins, Van der Meer, & Bleijenberg, 2006; Van Koulil et al., 2007). However, a recent trial of group-based CBT for CFS found that CBT in a group-based format can be at least as effective as individual CBT, if not more so (Wiborg, van Bussel, van Dijk, Bleijenberg, & Knoop, 2015). The possible superiority of group-based therapies, in this setting, may be linked to the validation and upward social comparisons that patients can provide one another, facilitating engagement.

Another key finding was that some participants expressed a strong attribution of CFS to organic causes, and this, coupled with the rejection of psychological explanations, seemed to impede engagement with CBT. This has been well-documented in the CFS literature

(Clements et al., 1997; Davison, Pennebaker, & Petrie, 1997; Larun & Malterud, 2007; Prins, Bleijenberg, Rouweler, van Weel, & van der Meer, 2000).

There was also a clear overlap in themes between the study here and the findings of Dennison et al. (2010). For example, like in Dennison's study, many participants here expressed a fear of relapses (Dennison et al., 2010). Moreover, studies have shown that ongoing fatigue is common despite CBT-related improvements (Dennison et al., 2010; Knoop, Bleijenberg, Gielissen, van der Meer, & White, 2007; Sharpe et al., 1996).

Before commencing treatment, participants had varied expectations about CBT. Some expressed uncertainty, whereas others saw it as a last resort and hoped for improvement. Perception of treatment as a last resort has also emerged in another qualitative study of psychological therapies across medically unexplained symptoms (MUS), including CFS, fibromyalgia, and chronic pain (Gerskowitch, Norman, & Rimes, 2015). A minority of participants expected CBT to cure their CFS, and for some high expectations seemed to lead to disappointment and a lower perception of improvement following treatment.. Previous research has also shown that patient expectations can impact upon treatment outcomes (Heins et al., 2013). Setting sights too high can result in disappointment, whereas being too pessimistic can result in poorer engagement with therapy (Bentall, Powell, Nye, & Edwards, 2002; Knoop, 2011; Prins et al., 2006; Westra, Aviram, Barnes, & Angus, 2010; Westra, Dozois, & Marcus, 2007). Positive outcome expectations may increase patients' perception of control, facilitating reductions in post-treatment fatigue (Heins et al., 2013). Therefore, outcome expectations need to be addressed and maximized at the start of treatment (Greenberg, Constantino, & Bruce, 2006).

Despite initial feelings of apprehension, participants often reported having learnt valuable skills and regained control over their lives through the process of CBT. Similar findings were reported in a qualitative study of psychological therapies across MUS (Gerskowitch et al., 2015). In support of the notion of self-compassion, a qualitative study of a rehabilitation programme for patients with non-specific chronic pain found it was important for patients to learn to set limits and adjust self-demands (Gustafsson, Ekholm, & Ohman, 2004). A quantitative study found that CBT was associated with an increase in perceived control over

fatigue, which in turn was predictive of improvements in fatigue severity (Heins, Knoop, Burk, & Bleijenberg, 2013; Prins et al., 2001). Moreover, studies have previously found that the benefits from CBT for CFS can be maintained long-term after treatment (Deale, Husain, Chalder, & Wessely, 2001; Flo & Chalder, 2014; White, Goldsmith, Johnson, Chalder, & Sharpe, 2013; White et al., 2011).

Clinical Implications

Overall, there was a consistent satisfaction with the services provided at the CFS unit. Even participants who did not report improvements described treatment as relevant and the therapist contact as supportive. The findings also highlight that sensitivity is paramount, especially when approaching the subject of beliefs patients may hold in relation to CFS. A solely psychological explanation of CFS may be alienating to some patients as it implies that they are responsible for their illness, and could be seen to implicitly blame them. Patients may come into CBT treatment having experienced delegitimation and stigma (Dickson, Knussen, & Flowers, 2007) which may shape their engagement with and experience of CBT (Banks & Prior, 2001). Providing patients with validation and recognition is critical, as it can facilitate the acceptance of psychological and social factors, alongside physiological ones (Chew-Graham, Brooks, Wearden, Dowrick, & Peters, 2010; Salmon, Dowrick, Ring, & Humphris, 2004). The CBT model acknowledges the role of both biological and psychosocial factors in the initiation and perpetuation of CFS, and this needs to be stressed in treatment.

This is important because, as mentioned previously, attribution style may influence engagement with treatment as well as treatment outcome. In this study, CBT appeared to provide validation and a chance for patients to talk about their struggles without being judged, facilitating engagement and contributing to the therapeutic effects of CBT, as has been previously documented (Barak, Hen, Boniel-Nissim, & Shapira, 2008; Dennison et al., 2010; Horvath et al., 2011). Thus, it is clear that sensitivity and compassion are needed in order not to alienate patients and to keep them engaged in CBT. Although the collaborative and non-judgemental approach is a fundamental aspect of CBT, additional considerations are necessary with regards to addressing causal beliefs and pre-treatment expectations in CBT

for people with CFS. It may be helpful to explicitly acknowledge the reality of the physical symptoms, incorporate physiological components of fatigue and describe the potential usefulness of CBT for other conditions such as inflammatory diseases.

Limitations of the Current Study and Future Directions

A limitation of this study is that it included only patients who were approaching the end of CBT or who had already completed CBT. Different themes may have emerged with patients who withdrew early from treatment; therefore, it would be valuable for future research to explore their experiences. To obtain accurate perceptions of patients and avoid recall bias, interviews could be conducted at different stages throughout the treatment process, as has been suggested by Dennison et al. (2010). The results may have been influenced by the overall response rate of 41%. However, other studies found comparable response rates in this patient population (Dennison et al., 2010; Moss-Morris, Petrie, & Weinman, 1996). Future studies could combine qualitative and quantitative methods, which would allow for triangulation.

Conclusion

In conclusion, this study suggests that beliefs about CFS may play a crucial role in CBT outcomes. Causal attributions may impact upon motivation and engagement with CBT. Further research is needed in order to explore how patients' beliefs may change as part of the treatment process and how to incorporate the findings from qualitative research into practice. The findings of this study may shed light on why some patients engage better with CBT than others. The results of this study suggest that various factors can moderate the effectiveness of CBT, and a further understanding of these factors may help to maximize its benefits and support patients who do not engage.

Acknowledgements

We would like to thank the patients, involved in this study, and therapists at the CFS unit for assistance with recruitment and data collection. This research received no specific grant from any funding agency, commercial or not-for-profit sectors. Professor Chalder receives research support from the Biomedical Research Centre for the South London and Maudsley NHS Foundation Trust and the Institute of Psychiatry. This organisation had no involvement in study design, collection of data, analysis, writing up, or decision to submit.

Ethical Approval

This study received ethical approval from South London and Maudsley's Psychological Medicine Clinical Academic Group Audit Committee and the clinical governance department, part of King's Health Partners, as an Audit and Service Evaluation Project.

References

- Baker, R., & Shaw, E. (2007a). Diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy): summary of NICE guidance. *Bmj*, 335(7617), 446-448.
- Baker, R., & Shaw, E. (2007b). Guidelines: diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy): summary of NICE guidance. *BMJ: British Medical Journal*, 335(7617), 446-448.
- Banks, J., & Prior, L. (2001). Doing things with illness. The micro politics of the CFS clinic. *Social science & medicine*, 52(1), 11-23.
- Barak, A., Hen, L., Boniel-Nissim, M., & Shapira, N. a. (2008). A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology in Human Services*, 26(2-4), 109-160.
- Bazelmans, E., Prins, J., Lulofs, R., Van der Meer, J., & Bleijenberg, G. (2005). Cognitive behaviour group therapy for chronic fatigue syndrome: a non-randomised waiting list controlled study. *Psychotherapy and psychosomatics*, 74(4), 218-224.
- Bentall, R., Powell, p., Nye, F. J., & Edwards, R. (2002). Predictors of response to treatment for chronic fatigue syndrome. *The British Journal of Psychiatry*, 181(3), 248-252.
- Bentall, R. P., Powell, P., Nye, F. J., & Edwards, R. H. (2002). Predictors of response to treatment for chronic fatigue syndrome. *The British Journal of Psychiatry*, 181(3), 248-252.
- Braun, V., & Clarke, V. *Successful qualitative research: A practical guide for beginners*: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Burgess, M., Andiappan, M., & Chalder, T. (2012). Cognitive behaviour therapy for chronic fatigue syndrome in adults: Face to face versus telephone treatment-A randomized controlled trial. *Behavioural and Cognitive Psychotherapy*, 40(02), 175-191.
- Castell, B. D., Kazantzis, N., & Moss-Morris, R. E. (2011). Cognitive Behavioral Therapy and Graded Exercise for Chronic Fatigue Syndrome: A Meta-Analysis. *Clinical Psychology: Science and Practice*, 18(4), 311-324.
- Cella, M., Chalder, T., & White, P. (2011). Does the heterogeneity of chronic fatigue syndrome moderate the response to cognitive behaviour therapy? An exploratory study. *Psychotherapy and psychosomatics*, 80(6), 353-358.
- Cella, M., Stahl, D., Reme, S., & Chalder, T. (2011). Therapist effects in routine psychotherapy practice: An account from chronic fatigue syndrome. *Psychotherapy Research*, 21(2), 168-178.
- Cella, M., White, P., Sharpe, M., & Chalder, T. (2013). Cognitions, behaviours and co-morbid psychiatric diagnoses in patients with chronic fatigue syndrome. *Psychological medicine*, 43(02), 375-380.
- Chalder, T., Butler, S., & Wessely, S. (1996). In-patient treatment of chronic fatigue syndrome. *Behavioural and Cognitive Psychotherapy*, 24(04), 351-365.
- Chambers, D., Bagnall, A.-M., Hempel, S., & Forbes, C. (2006). Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/myalgic encephalomyelitis: an updated systematic review. *Journal of the Royal Society of Medicine*, 99(10), 506-520.
- Chew-Graham, C., Brooks, J., Wearden, A., Dowrick, C., & Peters, S. (2010). Factors influencing engagement of patients in a novel intervention for CFS/ME: a qualitative study. *Primary Health Care Research and Development*, 12(2), 112.
- Clements, A., Sharpe, M., Simkin, S., Borrill, J., & Hawton, K. (1997). Chronic fatigue syndrome: a qualitative investigation of patients' beliefs about the illness. *Journal of psychosomatic research*, 42(6), 615-624.
- Crits-Christoph, P., Baranackie, K., Kurcias, J., Beck, A., Carroll, K., Perry, K., . . . Thompson, L. (1991). Meta-Analysis of Therapist Effects in Psychotherapy Outcome Studies. *Psychotherapy Research*, 1(2), 81-91.
- Dattilio, F. M., & Hanna, M. A. (2012). Collaboration in cognitive-behavioral therapy. *Journal of clinical psychology*, 68(2), 146-158.
- Davison, K. P., Pennebaker, J. W., & Petrie, K. (1997). Virtual narratives: Illness representations in online support groups. *Perceptions of health and illness: Current research and applications*, 463-486.

- Deale, A., Husain, K., Chalder, T., & Wessely, S. (2001). Long-term outcome of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome: a 5-year follow-up study. *American Journal of Psychiatry*, 158(12), 2038-2042.
- Dennison, L., Stanbrook, R., Moss-Morris, R., Yardley, L., & Chalder, T. (2010). Cognitive behavioural therapy and psycho-education for chronic fatigue syndrome in young people: Reflections from the families' perspective. *British journal of health psychology*, 15(1), 167-183.
- Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology and Health*, 22(7), 851-867.
- Flo, E., & Chalder, T. (2014). Prevalence and predictors of recovery from chronic fatigue syndrome in a routine clinical practice. *Behaviour research and therapy*, 63, 1-8.
- Fugard, A., & Potts, H. (2014). *Sample size determination for thematic analysis and related qualitative methodologies: a quantitative model*. Paper presented at the 6th ESRC: Research Methods Festival, St Catherine's College, Oxford
- Fukuda, K., Straus, S. E., Hickie, I., Sharpe, M. C., Dobbins, J. G., & Komaroff, A. (1994). The chronic fatigue syndrome: a comprehensive approach to its definition and study. *Annals of internal medicine*, 121(12), 953-959.
- Gerskowitch, C., Norman, I., & Rimes, K. A. (2015). Patients with medically unexplained physical symptoms experience of receiving treatment in a primary-care psychological therapies service: a qualitative study. *The Cognitive Behaviour Therapist*, 8, e12.
- Greenberg, R. P., Constantino, M. J., & Bruce, N. (2006). Are patient expectations still relevant for psychotherapy process and outcome? *Clinical psychology review*, 26(6), 657-678.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), 59-82.
- Gustafsson, M., Ekholm, J., & Ohman, A. (2004). From shame to respect: musculoskeletal pain patients' experience of a rehabilitation programme, a qualitative study. *Journal of Rehabilitation Medicine*, 36(3), 97-103.
- Guy, W. (1976). Clinical global impression scale. *The ECDEU Assessment Manual for Psychopharmacology-Revised Volume DHEW Publ No ADM*, 76(338), 218-222.
- Heins, M., Knoop, H., & Bleijenberg, G. (2013). The role of the therapeutic relationship in cognitive behaviour therapy for chronic fatigue syndrome. *Behaviour research and therapy*, 51(7), 368-376.
- Heins, M. J., Knoop, H., Burk, W. J., & Bleijenberg, G. (2013). The process of cognitive behaviour therapy for chronic fatigue syndrome: Which changes in perpetuating cognitions and behaviour are related to a reduction in fatigue? *Journal of psychosomatic research*, 75(3), 235-241.
- Horvath, A., Del Re, A., Flückiger, C., & Symonds, D. (2011). Alliance in individual psychotherapy. *Psychotherapy*, 48(1), 9.
- Houdenhove, B. v., & Luyten, P. (2008). Customizing treatment of chronic fatigue syndrome and fibromyalgia: the role of perpetuating factors. *Psychosomatics*, 49(6), 470-477.
- Joyce, J., Hotopf, M., & Wessely, S. (1997). The prognosis of chronic fatigue and chronic fatigue syndrome: a systematic review. *Qjm*, 90(3), 223-233.
- Knoop, H. (2011). Cognitive Behavior Therapy for Chronic Fatigue Syndrome: Where to Go From Here? *Clinical Psychology: Science and Practice*, 18(4), 325-330.
- Knoop, H., Bleijenberg, G., Gielissen, M. F., van der Meer, J. W., & White, P. D. (2007). Is a full recovery possible after cognitive behavioural therapy for chronic fatigue syndrome? *Psychotherapy and psychosomatics*, 76(3), 171-176.
- Larun, L., & Malterud, K. (2007). Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient education and counseling*, 69(1), 20-28.
- Malouff, J. M., Thorsteinsson, E. B., Rooke, S. E., Bhullar, N., & Schutte, N. S. (2008). Efficacy of cognitive behavioral therapy for chronic fatigue syndrome: a meta-analysis. *Clinical psychology review*, 28(5), 736-745.
- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1(1), 15-25.

- Petrie, K., Moss-Morris, R., & Weinman, J. (1995). The impact of catastrophic beliefs on functioning in chronic fatigue syndrome. *Journal of psychosomatic research*, 39(1), 31-37.
- Price, J. R., Mitchell, E., Tidy, E., & Hunot, V. (2008). Cognitive behaviour therapy for chronic fatigue syndrome in adults. *Cochrane Database Syst Rev*, 3.
- Prins, J. B., Bleijenberg, G., Bazelmans, E., Elving, L. D., de Boo, T. M., Severens, J. L., . . . Van der Meer, J. W. (2001). Cognitive behaviour therapy for chronic fatigue syndrome: a multicentre randomised controlled trial. *The Lancet*, 357(9259), 841-847.
- Prins, J. B., Bleijenberg, G., Rouweler, E. K., van Weel, C., & van der Meer, J. W. (2000). Doctor-patient relationship in primary care of chronic fatigue syndrome: perspectives of the doctor and the patient. *Journal of Chronic Fatigue Syndrome*, 7(4), 3-15.
- Prins, J. B., Van der Meer, J. W., & Bleijenberg, G. (2006). Chronic fatigue syndrome. *Lancet*, 367(9507), 346-355.
- Quarmby, L., Rimes, K. A., Deale, A., Wessely, S., & Chalder, T. (2007). Cognitive-behaviour therapy for chronic fatigue syndrome: comparison of outcomes within and outside the confines of a randomised controlled trial. *Behaviour research and therapy*, 45(6), 1085-1094.
- Rimes, K. A., & Chalder, T. (2005). Treatments for chronic fatigue syndrome. *Occupational medicine*, 55(1), 32-39.
- Roberts, A., Charler, M.-L., Papadopoulos, A., Wessely, S., Chalder, T., & Cleare, A. (2010). Does hypocortisolism predict a poor response to cognitive behavioural therapy in chronic fatigue syndrome? *Psychological medicine*, 40(03), 515-522.
- Salmon, P., Dowrick, C. F., Ring, A., & Humphris, G. M. (2004). Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *British Journal of General Practice*, 54(500), 171-176.
- Sharpe, M., Hawton, K., Seagroatt, V., & Pasvol, G. (1992). Follow up of patients presenting with fatigue to an infectious diseases clinic. *BMJ: British Medical Journal*, 305(6846), 147.
- Sharpe, M., Hawton, K., Simkin, S., Surawy, C., Hackmann, A., Klimes, I., . . . Seagroatt, V. (1996). Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial. *Bmj*, 312(7022), 22-26.
- Stahl, D., Rimes, K., & Chalder, T. (2014). Mechanisms of change underlying the efficacy of cognitive behaviour therapy for chronic fatigue syndrome in a specialist clinic: a mediation analysis. *Psychological medicine*, 44(06), 1331-1344.
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: a cognitive approach. *Behaviour research and therapy*, 33(5), 535-544.
- Timmer, B., Bleichhardt, G., & Rief, W. (2006). Importance of psychotherapy motivation in patients with somatization syndrome. *Psychotherapy Research*, 16(03), 348-356.
- Van Koulil, S., Effting, M., Kraaijmaat, F., Van Lankveld, W., Van Helmond, T., Cats, H., . . . Evers, A. (2007). Cognitive-behavioural therapies and exercise programmes for patients with fibromyalgia: state of the art and future directions. *Annals of the rheumatic diseases*, 66(5), 571-581.
- Wearden, A., Dunn, G., Dowrick, C., & Morriss, R. (2012). Depressive symptoms and pragmatic rehabilitation for chronic fatigue syndrome. *The British Journal of Psychiatry*, 201(3), 227-232.
- Wessely, S., Hotopf, M., & Sharpe, M. (1998). *Chronic fatigue and its syndromes*: Oxford University Press Oxford.
- Westra, H. A., Aviram, A., Barnes, M., & Angus, L. (2010). Therapy was not what I expected: A preliminary qualitative analysis of concordance between client expectations and experience of cognitive-behavioural therapy. *Psychotherapy Research*, 20(4), 436-446.
- Westra, H. A., Dozois, D. J., & Marcus, M. (2007). Expectancy, homework compliance, and initial change in cognitive-behavioral therapy for anxiety. *Journal of Consulting and Clinical Psychology*, 75(3), 363.
- White, P., Goldsmith, K., Johnson, A., Chalder, T., & Sharpe, M. (2013). Recovery from chronic fatigue syndrome after treatments given in the PACE trial. *Psychological medicine*, 43(10), 2227-2235.
- White, P. D., Goldsmith, K., Johnson, A., Potts, L., Walwyn, R., DeCesare, J., . . . Cox, D. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded

- exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet*, 377(9768), 823-836.
- Whiting, P., Bagnall, A.-M., Sowden, A. J., Cornell, J. E., Mulrow, C. D., & Ramírez, G. (2001). Interventions for the treatment and management of chronic fatigue syndrome: a systematic review. *Jama*, 286(11), 1360-1368.
- Wiborg, J. F., Knoop, H., Wensing, M., & Bleijenberg, G. (2012). Therapist effects and the dissemination of cognitive behavior therapy for chronic fatigue syndrome in community-based mental health care. *Behaviour research and therapy*, 50(6), 393-396.
- Wiborg, J. F., van Bussel, J., van Dijk, A., Bleijenberg, G., & Knoop, H. (2015). Randomised controlled trial of cognitive behaviour therapy delivered in groups of patients with chronic fatigue syndrome. *Psychotherapy and Psychosomatics*, 84(6), 368-376.

1. What were your expectations of treatment before you came here to the CFS Unit?
2. Do you feel that your expectations of treatment were met? Can you please elaborate on that?
3. How are you feeling now compared to before you started treatment?
4. Did you find any difficulties with the process of attending treatment sessions?
5. What was your experience of using materials such as sleep diaries and activity monitoring sheets as part of the treatment process?
6. Were there any other aspects of your treatment which you found useful and could you tell me a little bit more about this in detail?
7. Did you find any aspects of your treatment were not useful and could you elaborate?
8. Do you think that the treatment was appropriate for you?
9. Do you feel that the length of treatment was appropriate?
10. Can you tell me a little bit more about the process of CBT?
11. Do you think the treatment requires contact with the therapist?
12. What advice would you give to someone who has been just diagnosed with CFS?
13. Would you recommend CBT to other patients with CFS?
14. Is there anything else you would like to add?

Figure 1. Interview schedule.

Table 1

Demographics of Participants

Participant (pt) Number	Age Range	Gender	Ethnicity
1	35-44	F	White
2	25-34	F	White
3	25-34	F	White
4	25-34	F	White
5	25-34	F	White
6	25-34	M	White
7	45-54	F	White
9	25-34	F	Black or Black British
10	35-44	F	White
11	25-34	F	White
12	45-54	M	White
13	18-24	F	Black or Black British
14	55-64	F	White

Table 2

Satisfaction and Wellbeing Ratings

Participant (pt) Number	Satisfaction with CBT outcome	Wellbeing post CBT
1	Very Satisfied	Much Better
2	Very Satisfied	Much Better
3	Slightly Satisfied	A Little Better
4	Very Satisfied	Very Much Better
5	Moderately Satisfied	A Little Better
6	Very Satisfied	Very Much Better
7	Moderately Satisfied	A Little Better
9	Very Satisfied	Very Much Better
10	Very Satisfied	Much Better
11	Moderately Satisfied	Much Better
12	Very Satisfied	Much Better
13	Slightly Dissatisfied	Very Much Worse
14	Very Satisfied	Very Much Better

Table 3

Summary of the Recurrent Themes and Subthemes across the Narratives

Themes	Subthemes
1. Hopes and Expectations	1.1 Mixed feelings
	1.2 Previous experiences of treatment
2. Real, Not Imagined	2.1 Validation and the process of diagnosis
	2.2 Causal attributions
	2.3 Stigma
3. Collaborative Therapeutic Alliance	3.1 CBT as support
	3.2 Rapport
	3.3 Personalised care
4. Motivation and Engagement	4.1 Acceptability of psychological explanations
	4.2 Intrinsic motivation
	4.3 Challenges of CBT
5. Gain and Loss	5.1 Gaining insight
	5.2 Gaining self-management strategies
	5.3 Gaining self-compassion
	5.4 Losing favoured activities
	6.1 Usefulness of CBT-specific components

	6.2 Awareness of change
6. Change	6.3 Before and now
	6.4 Transitioning out of treatment

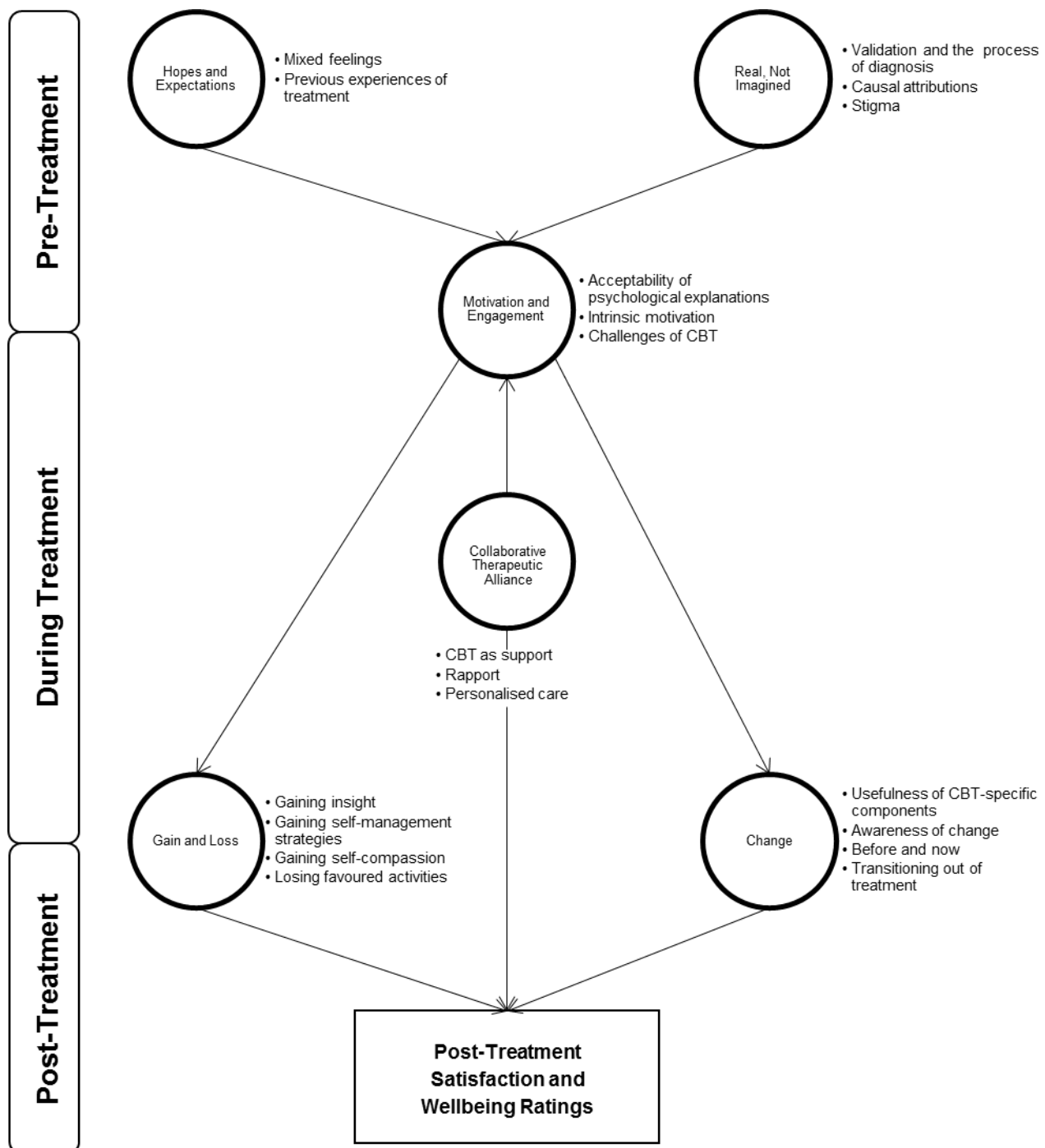


Figure 2. Thematic diagram of the identified themes and subthemes.